

SPINAL COURIER

The spinal cord disability information source for Arkansans since 1989

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Dan Stell Retires

ASCC Case Manager Dan Stell announced his retirement effective February 23, 2001. Dan had been employed as a Case Manager in the Little Rock office since 1982. Previous to his tenure with ASCC. Dan began his state career in 1969 with the Arkansas Rehabilitation Services. His dedication and untiring efforts will be missed by those individuals he served.

Dan's relaxed and steady manner always put people at ease. This attribute has enabled him to develop the confidence and trust

necessary for positive working relationships with the individuals he has served, as well as with other professionals.

In addition to instilling confidence in others, Dan was often considered "the stable force" in the Little Rock Case Management Office. His years of experience provided invaluable leadership to many new Case Managers.

"As a Case Manager Dan was always there to help with a problem Continued on page 4 - see "Dan Stell Retires"



Dan Stell admires the cake at the luncheon honoring his retirement.

New Medicaid Working Disabled Coverage Available

A new option for Medicaid coverage is now available that will allow SSI recipients to go to work but maintain their Medicaid coverage, based on their income. The program is an employment initiative designed to serve as a "bridge" to enable people with disabilities to gain employment without losing Medicaid benefits.

The program was mandated by Act 1197 of 1999 and the staff at Department of Human Services (DHS) have worked diligently to establish the program, in accordance with similar federal legislation. The new Working Disabled (WD) program is Aid Category 10, which became effective on February 1, 2001.

Eligibility requirements for this new program include:

- A. Are 16 to 64 years old.
- B. Are disabled according to Supplemental Security Income (SSI) disability criteria.
- C. Are employed in any ongoing work activity for which income is received.
- D. Have a net countable income under 250% of the federal poverty level. This would be \$1,739 for an individual, \$2,343 for a family of two, \$3,552 for a family of four, etc.

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SPINAL COURIER

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With Thanks

Donations this quarter from:

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ASCC accepts tax deductible donations. The generosity of the many individuals and families, who over the years have made memorial donations, is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at 501-296-1788 / 800-459-1517 (voice) / 501-296-1794 (TDD), or send your donation to:

AR Spinal Cord Commission 1501 N. University, Suite 470 Little Rock, AR 72207

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SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

See You On The River!

Dear Editor:

I am working with the Arkansas Canoe Club to develop an adaptive canoeing program for individuals with disabilities. The Canoe Club plans to host two clinics in different areas of the state this year to teach adaptive skills and to get persons with disabilities involved in canoeing. It's a great outdoor activity that can be done with friends, family or the club on Arkansas' many rivers and lakes.

Interested individuals for the first programs would need to have hand strength, upper body strength and at least fair trunk balance—this would probably include those with paraplegia below T₆.

If you are interested in this exciting opportunity, at no cost to the participant, please contact me at **501-361-2539**. See you on the river!

Tammy Graham, OTR Fayetteville, AR

From the Director

A dear friend passed this story along to me the other day and I thought it was well worth sharing with you.

A group of frogs were traveling through the forest and two of them fell in a deep pit. All the other frogs gathered around the pit. When they saw how deep it was, they yelled down to the fallen frogs that they would never get out. The two frogs ignored them and jumped and jumped trying to get out of the pit. The frogs above kept telling them they were as good as dead. Finally one frog took heed to the yells, gave up, fell over and died. The other frog just jumped harder and higher. The frogs above kept yelling to him to stop the pain and suffering and give up. He kept jumping and finally got high enough to make it out.

When he got out, the other frogs were amazed. "Why did you keep jumping? Didn't you hear us?" "No," the frog motioned—he was deaf. As he had looked up from the pit, he thought they were encouraging him and cheering him on!

Two lessons from the frogs:

- 1. There is the power of life and death in the spoken word. An encouraging word to someone who is down can lift them up and help them make it through the day.
- 2. A destructive word to someone who is down can be all it takes to make them give up, to kill their spirit.

Speak life to those who cross your path. Special is that individual who takes the time to encourage others.

Enjoy the spring and watch out for the frogs!

Cheryl Vines

Time to Sign Up for Camp!

Spring has arrived and it is time to get ready for our annual Spina Bifida Camp. Every year the Arkansas Spinal Cord Commission, in cooperation with MedCamps of Arkansas, Inc. and Camp Aldersgate, Inc., sponsors a week long session of camping for children between the ages of six and sixteen at Camp Aldersgate in West Little Rock. This year's camp will be held from June 24 through June 29, 2001.

For those of you unfamiliar with camp, Camp Aldersgate is located in West Little Rock. The traditional camping activities such as nature hikes, outdoor cooking, arts and crafts, swimming, fishing, drama and music are featured. These activities have been adapted so that each camper can participate to his

or her fullest ability.

All of the cabins, dining hall, health care center and activity buildings are air conditioned and fully accessible. In addition, from the time camp starts on Sunday afternoon until camp ends on Friday morning, the campers are supervised by trained counselors, volunteers and MedCamps medical specialists.

This really is a time of growth and learning for all of the campers while they spend a week full of fun-filled activities. Applications and brochures were sent out in March and acceptance will be based on a first-come, first-served basis—so be sure to send yours in as soon as possible!

Working Disabled Program

Continued from page 1

E. Have countable resources equal to or less than the Medicaid resource level for the household size. A Working Disabled recipient may have funds in an "approved account" which may be used to enhance independence or employability (such as assistive technology or work related expenses such as personal care assistance). This account must be approved by DHS.

Medicaid recipients in the WD category will receive a full range of Medicaid benefits in accordance with Medicaid guidelines. However, there will be a new cost sharing copayment plan established for those recipients with incomes over 100% and up to 250% of the federal poverty level.

The copays are nominal, not unlike the cost of a typical health maintenance organization. For example, a physicians visit copay is \$10, emergency department visit \$10, home health or therapy \$10 per visit and durable medical equipment 20% of the Medicaid maximum allowable. Prescription coverage is also available.

This innovative new program is not for everyone, but it will provide a great opportunity for those who want to move back into the workforce but are fearful of losing their needed medical coverage. It allows those who work in jobs where there is no health insurance to maintain Medicaid coverage, up to a certain income.

If you are interested in applying for the new Working Disabled Category 10 coverage, you may apply at your local Department of Human Services County office. If you have questions related to eligibility, you may contact DHS Customer Assistance at **1-800-482-8988**.

SBA/AR College Scholarship Program

For the 2001-2002 school year the Spina Bifida Association of Arkansas (SBA/AR) offers four college scholarships of \$500 each to graduating high school students, those who have already graduated or those currently attending a college, university or vocational-technical school.

Eligibility requirements are:

- 1. Have spina bifida.
- 2. Reside in the state of Arkansas.
- 3. Have been accepted to a college, university or vocational-technical school for the school year beginning in the fall of 2001.
- 4. Complete an application that includes a written essay, proof of acceptance or registration for the fall semester and letters of recommendation.
- 5. Applications must be received by the SBA/AR no later that August 15, 2001.

All applicants will be notified by September 1, 2001, as to whether or not they have been awarded a scholarship. Past recipients of scholarships are eligible to apply. However, first consideration will be given to those who have not previously received a scholarship.

To obtain an application, call **501-978-7222**. Mail completed applications, together with supporting documents, to:

Spina Bifida Assn of AR PO Box 24663 Little Rock, AR 72221

Don't forget to check with counselors at your high school and at the schools where you might decide to attend for other sources of financial assistance.

SPINAL COURIER — 3

Freehand System for Quadriplegics

By Tom Kiser, M.D., ASCC Medical Director

When I see patients in clinic we often talk about recent spinal cord research and what is new in the medical treatment of individuals with spinal cord injuries. One recent innovation that can help individuals with C_5 to C_6 quadriplegia is the Freehand system.

This is an implantable device that bypasses the damaged spinal cord and directly stimulates the muscles of your arm by using electricity. A pacemaker-like device implanted under your skin sends electrical signals to the muscles of your wrist and hand. For properly selected individuals with loss of upper and lower extremity movement, it can help restore use of a paralyzed hand and improve their level of independence.

The Freehand system provides electrical stimulation that can help restore grasp and pinch to individuals with spinal cord injuries. The device is an electromagnetic receiver about the size of a pacemaker, which is implanted under the skin on the chest. Wires run from the receiver to the muscles we want to stimulate. Up to eight separate muscles can be stimulated. The receiver is powered by

a transmitting electromagnetic coil, which is taped to the skin over the receiver by an aide or family member and then connected to a battery-powered power source attached to the wheelchair. Impulses to the paralyzed arm are sent by moving the opposite shoulder, which has a telescoping control unit taped to the shoulder.

The Freehand system can be a powerful tool to help an individual with no hand function regain enough hand function to do many tasks that previously were impossible. Some tasks that the Freehand system can help individuals perform are eating and drinking, brushing teeth, combing hair, writing with a pen/pencil, using a telephone, inserting a floppy disk or handling larger objects such as video tapes and books.

Not everyone with quadriplegia is a candidate for the Freehand system. Your muscles have to be able to be stimulated by electricity. You cannot have a pressure sore or an active infection. You have to be willing to participate in a home program with a surface stimulation unit for one to two months to strengthen the muscles in your



arm in preparation for surgery. You have to be able to live with your arm immobilized in a cast for up to six weeks after surgery. Finally, you have to participate in an aggressive rehabilitation program postoperatively to learn how to use the system effectively. If you do not qualify for the Freehand system, you may be a candidate for tendon transfers to help restore hand function.

Presently the only location in Arkansas working with the Freehand system is the Baptist Health Medical Center in Little Rock. If you are interested in being evaluated for the Freehand system, contact the Baptist Health Rehabilitation Institute Outpatient clinic at **501-202-7520**, and they can tell you what steps to take to be scheduled for an evaluation.

Dan Stell Retires

Continued from page 1

and he didn't quit until a solution was found," said ASCC Client Services Administrator Patti Rogers. This opinion was shared by clients, coworkers and friends alike. Dan's persistence will be missed at ASCC.

The Commission honored Dan with a luncheon February 22 at

the Bella Italia Restaurant. His wife Annie and daughter Dawn were present as ASCC staff, former coworkers and friends paid tribute to Dan and wished him well. On behalf of the Arkansas Spinal Cord Commission, Executive Director Cheryl Vines presented Dan with a plaque in recognition of his many years of service to the agency and to individuals with spinal cord disabilities.

Rumor has it that Dan and Annie are already planning a trip to China in the near future. Until then, those of us travelling down Interstate 40 won't be surprised to see Dan some morning casting a line or two on the waters of Lake Conway.

Whatever his future endeavor we know that it will be successful and we wish him the best!

Grief and Loss Due To Disability

By Bernie Quell, ASCC Case Manager, Little Rock, AR

Many newly disabled individuals with a spinal cord injury (SCI) never fully realize the extent of their personal loss until months after the incident. Some individuals enjoy a celebrity status while in the hospital. They are surrounded by family and friends and well-wishers. They are the attention of hospital personnel and rehabilitation specialists. Staff meetings with several professionals are held to assess and promote progress, gains and limitations.

The initial assumption of many individuals with any catastrophic injury is: "I can beat this. This is just a temporary setback." After awhile reality rears its ugly head, and what was seen as "temporary" becomes a living nightmare.

At this time, it is normal to be angry. It is normal to be grief stricken. It is normal to want back what has been lost. There is the physical loss of function to the body.

Your challenge is to work

toward accepting your

"normal" situation as it now

presents itself to you.

There is also secondary loss—this is loss due to your dreams of life which may never

occur now. There is the loss of certain activities that you may never participate in again. There is loss due to immediacy and spontaneity. Things you used to do on your own now require planning and assistance from others. Your reality becomes one of being dependent on others.

Many individuals with SCI get caught in attempting to recreate events that led up to the incident. Many of their statements begin with "If only . . . , if only . . . , if only " Many individuals take their hurt and frustration out on their family and loved ones. The injury does not only affect the victim. Their loved ones are grieving also. All of this emotional pain is sometimes more difficult to understand than the physical loss.

So what can be done?

There are no easy answers. This is a situation where there is no quick fix. Permanent is permanent. Acceptance is the first step. You were not a fool to think that all of this would go away and everything would go back to normal. From here on out, this is normal. It is likely not what you ever would have chosen for yourself—however, this is the normal you are dealing with now.

Your challenge is to work toward accepting your "normal" situation as it **now** presents itself to you.

Again, it's not easy. You need to be able to express your anger and frustration in ways that are not hurtful to yourself or to others.

Using alcohol and drugs will not make things better. When you sober up, you are still who and what you are. Drugs and alcohol help with avoidance. **The key here is acceptance**. Drugs, alcohol and anger usually cover up the true feelings that an individual is attempting to avoid. Getting mad and angry at those closest to you does not help you or them.

Maybe you could talk with a loved one by saying: "I am afraid of all of the changes in my life. I don't know if I can handle all of it. All I know is that I am very frightened."



Honest and open communication with a loved one or a trusted friend is so very important.

Communication is a direct link to acceptance, which leads to changes in your attitude. The worst thing that any person can experience is feeling so alone that no one could ever understand their situation. There is a lot of value placed on independence, but the truth of the matter is that we all need one another.

Allow yourself the opportunity to express your loss in healthy and helpful ways. In the right situation, ask your loved ones how they have been affected by SCI. Steps to aim for include:

- Talk with others openly and honestly.
- Readjust your attitude.
- Work toward acceptance.
- Share your feelings.
- Find out from others how they are coping.

Again, it's not easy. It is reaching out to others. It is a step toward recovery of your loss.

SPINAL COURIER — 5

Two-mile Trek to Class Does Not Stop Wheelchair-bound Student

By Daniel Childers, ASU Graduate in Journalism e-mail address: dlc42098@yahoo.com

I will never forget November 17, 1991. I was cutting deli meat at Bruce's Market in Jonesboro, AR when the phone rang.

I smelled the pressed ham on my hands as I picked up the phone. My father told me my best friend, Junior Mosley, had been shot in the back of the neck by his stepfather for defending his mother during an argument.

Junior was a sophomore at Jonesboro High School. He was a slender handsome black kid from the north side of Jonesboro. I remember his big white-toothed smile. Standing a couple of inches over six feet, he was a quiet individual who avoided trouble at all costs. He was a promising basketball player about to start for the varsity team. He excelled in academics as well as athletics, in case basketball

"I am just happy to be

here and look forward

to school the next day.

That's my philosophy —

live life day by day and

you'll be happier,

and I am."

didn't work out. Well, it didn't.

I was confused, angry, anxious and frustrated after I heard the news. However, I showed no emotions as my father, who was

as upset as I was, comforted me and drove me to the hospital. At 16 years old, I never imagined this could happen so close to home.

I walked in the hospital expecting the best. I saw Junior, his head lying in a pool of blood, and he was unconscious. Just the day before we had played one-on-one and cracked jokes like most best friends. Now my friend appeared to be dead.

A doctor told me Junior might live. I stayed in the hospital the first night trying to understand the extent of my friend's injuries. The

longer I stayed, the more confused I became. The only information I received was that my friend would not die that day, and that he would never walk again.

I visited my friend. He had a breathing tube protruding from his neck and a feeding tube poking out of his belly. I told him if there was anything I could do, to just let me know.

Junior gradually got better. The tube was removed from his neck and he could eat solid food. He even had his own floor to himself.

Everyone went to see him and cared about him. Basketball coaches and the basketball teams visited him, and elementary schools sent him cards with the name of every kid in the school. This lasted for a few months until he was released

from the hospital. He stayed in town for a while and then left for a rehabilitation center in Hot Springs.

After his move to Hot Springs, the contact be-

tween the two of us dwindled from once per day to maybe one call a week. I visited him in Hot Springs, and he appeared to be getting better.

He is a high quadriplegic and has minimal use of his hands. He can't write or brush his teeth without a prosthesis.

After the shooting, Junior was mad at the world and he was sour most of the time, but who wouldn't be after that trauma?

He stayed in Hot Springs for about five years, and came to Jonesboro



Allister Mosley Jr. begins his two-mile journey to Arkansas State University from his home in north Jonesboro. Despite many difficulties, he continues to pursue a college degree. Photo by Daniel Childers

for holidays. Junior moved to Little Rock when he was done with rehab in Hot Springs.

Our conversation went from once a week to about once a month. We still called each other on birthdays; we always remembered those days.

One day Junior called. He said he had been sitting at the house by himself watching television. "I heard a knock at the door. I asked who it was and someone said David. I looked out of the peephole and noticed it was one of my friends, so I opened the door."

"He came in with three other people, two guys and a girl. The girl asked if she could use the bathroom, and I said yes. Next thing I know, my friend hit me in the back of the head. I turned and he stabbed me in the eye and then three or four times in the back of the neck."

"If that wasn't enough, the girl was taking my stuff and the two other guys were saying 'don't move or we'll shoot you.' I said where can I go in this wheelchair?"

After that, Junior decided to return to Jonesboro.

Continued on page 7 - see "Two-Mile Trek to Class"

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Two-mile Trek to Class

Continued from page 6

Since his return, I have realized the importance of missed friends.

He lost his sight in one eye and looks pretty much like he did before the shooting, although he is about 40 pounds heavier and is hunched over in a wheelchair.

He lives in a one-person house with his sister and three of her kids on his disability check. Junior enrolled at ASU this fall and he rides his wheelchair almost two miles to and from classes.

"I decided to go to school for a few reasons. One, I don't want to sit at home doing nothing. It gets very boring and depressing. Two, it makes me have a sense of self worth. It's something positive. Three, I really need an education," Junior said.

Junior never fails to call on my birthday. This year, he bought me my favorite present, a cordless drill. I told him he didn't have to get me anything. He said with that one-of-a-kind smile, "I know, but every time you come to fix my stuff that is the only damn tool you are missing and that is always the one you need."

I see him on campus regularly and we admire decent looking women and talk about old times. Sometimes we discuss the squirrels leaping from tree to tree. The next day we might talk about playing ball like we did at the City Water and Light Park on Cherry Street. Whatever the topic, we always have something to say.

Since his return to Jonesboro, Junior's attitude toward life has changed for the better. "Well, I thought for a year about the things I have been through. The only thing worse could be death and I have been close to that a few times," he said. "I am just happy to be here and look forward to



Internet Life

Yes, the days are getting longer and warmer. Spring time is right around the corner. April showers, cool sunny days, flowers in bloom, picnics, spring cleaning, travel, romance! Sounds inviting—especially that romance part. If you're interested, you may want to check out these web sites:

Sexuality information, education, counseling, therapy, medical aspects and other resources are available at http://www.sexualhealth.com.

Romance tips, advice, communication solutions, personal stories and other related information can be found at http://inlove.org.

If you're planning a trip, especially on commercial carriers, visit these sites for valuable tips:

Good and bad experiences of disabled travelers at hotels, airlines and restaurants are related at http://www.geocities.com/Paris/1502/.

Look for travel information, links, and discussion groups for people with disabilities at http://www.access-able.com/.

school the next day. That's my philosophy—live life day by day and you'll be happier, and I am."

So, if you are driving on Aggie in the rain and see a black guy in a wheelchair taking his time riding down the middle of the street, remember he has already ridden at least a mile. His wheelchair only goes eight miles per hour and he probably will be on campus in about 10 or 15 minutes, and you can bet he'll be there.

He's lived through hell, and is riding through the high water to get to class.

Reprinted with permission courtesy of The Herald of Arkansas State University, December 5, 2000, page 4. More travel information, discussions and resources are available at http://gimponthego.com.

If you're thinking about trading your old wheelchair in for a new model (don't ya wish), you might want to visit http://www.wheel chairjunkie.com. There you'll find critiques, information and discussion about specific models of chairs from users themselves to help in your decision process.

So, where have you been on the Internet? We would like to hear from you at arkscc@aol.com.

Watch What You're Doing!

By Don Bragdon, London, AR

About three months ago I burned my knee with boiling hot water while sterilizing my catheters on the stove. I have been doing this for over five years, but this was the first time I spilled the water.

Not watching what I was doing, I had rolled over to pull the pot off the burner when it started boiling and the hot water spilled on my knee. I didn't know I had burned myself until I got in bed and pulled off my stockings—the skin came off with them! A spot about the size of a dollar bill had burned, and it's still not completely healed.

Now I put a heavy piece of plastic with a double thickness towel under it over my legs when I'm boiling water (a plastic garbage bag with a thick towel will work). That way, it will deflect the water off my legs if I spill any. Also, when I'm in my shop welding, I put a rawhide apron on my lap in case I drop anything hot.

The problem in injuring yourself is not thinking what could happen. You have to watch what you do!

SPINAL COURIER — 7

ADSA Trap Shoot

The Arkansas Disabled Sportsman Association (ADSA) is sponsoring a Trap Shoot on May 5, 2001. The cost of this event is \$10 for each participant. You do not have to be disabled to participate in this event. All participants' names will be placed in a hat (one for disabled/one for non-disabled) and teams will be drawn from them. Trophies will be awarded and snacks will be provided. The \$10 entry fee will cover the cost of the clays and shells for the round.

Fishing outings can be scheduled if any members are interested. Dove, squirrel, deer and duck hunts are being scheduled for the fall, but dates have not yet been set.

ADSA hopes you will participate, and would like to ask that, if you have any suggestions or ideas of events, please feel free to call **870-933-5254**.

Check Out These Books!

The McCluer Education and Resource Center on Spinal Cord Injury has added a number of new items to its collection. If you are interested in checking out any of the resources, please call the Resource Center at 501-296-1792 or 800-459-1517. It's spring and time to get in shape! Three good books on fitness include:

- Toward Fitness: Guided Exercise for Those with Health Problems provides clearly described exercise and sports programs specifically tailored to overcome individual physical problems such as obesity, diabetes, back pain, advanced age, long inactivity, loss of limb and after effects of a heart attack, to name a few of the disabilities affecting a great majority of the population.
- Physical Fitness: A Guide for Individuals with Spinal Cord Injury offers a solid foundation in understanding the importance of physical fitness and the ways in which persons with SCI can achieve, maintain and enjoy keeping fit. Several SCI levels are covered and variations on how the desired exercises and sports activities can be accomplished are included.
- Conditioning with Physical Disabilities provides conditioning activities and programs specifically designed to help you enjoy and benefit from regular exercise, regardless of your disability. It was written to expand the knowledge base on strength conditioning for you, coaches, and professionals.

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